Chart Abstractor Codebook
for
Project to Improve Communication in Serious Illness – Pilot Study (PICSI-P)

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Overview

This codebook is the product of a collaborative effort by its authors to identify and operationalize working definitions for content domains commonly encountered in clinician documentation of serious illness communication in the UW Medicine electronic health record. Following a literature-informed drafting of a preliminary codebook, the authors engaged in an iterative process of descriptive coding, deliberation, and refinement of coding definitions and examples to arrive at the codebook presented. This process was informed by qualitative abstraction of free-text electronic health records belonging to a broad array of outpatients and inpatients with serious illness. The team met weekly over a 4-month period to arrive at a consensus for coding instructions, definitions, and examples.

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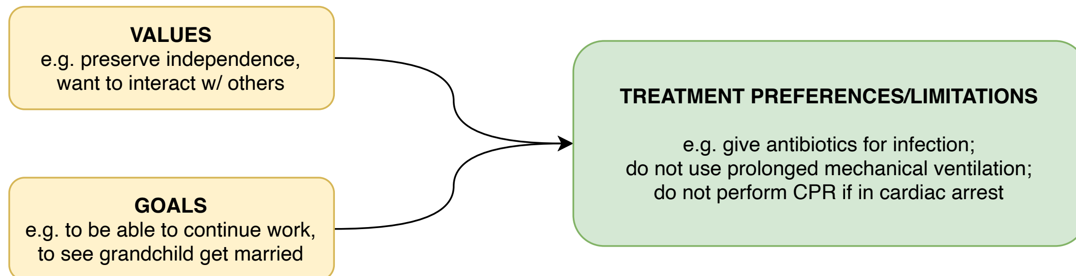
Identifying Goals-of-Care Discussions in the EHR

What are "Goals of Care"?

Goals of care (GOC) is a term that refers to "the overarching aims of medical care for a patient." These overarching aims might include some combination of priorities surrounding life extension, avoiding disability, relief from pain or discomfort, or other goals. Ideally, goals of care should be "informed by patients' underlying **values and priorities**, established within the existing clinical context, and used to guide **decisions about the use of, or limitation(s) on, specific medical interventions**." [Secunda et al, JGIM 2019]

Conversations between patients, families, and clinicians about goals of care are common among patients with serious illness. These conversations are referred to as **goals of care discussions**. These discussions may be prompted by a chronic, life-limiting medical condition; by a significant clinical event, such as a hospitalization; and/or, by the development of a new acute illness for which a decision regarding specific treatments must be made at that time.

A GOC discussion may include discussion of values, goals, and treatment preferences/limitations. While the ideal GOC discussion always includes all three elements, real-life documentation often does not include all three elements.



Project Objective

Our goal is to measure **documentation of conversations with patients and families about goals of care.** As the exact definition of what constitutes a GOC discussion may change from study to study depending on the research question being asked, this codebook will define several different domains of documentation of GOC that will serve future studies measuring the timing, frequency, and nature of GOC discussions, and their documentation in the EHR.

Related Terminology

Advance care planning (ACP): "A process that supports adults in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." [Sudore et al]

ACP forms/documents: Specific (usually paper) forms used to codify and document the results of advance care planning, often by translating them into specific directives or treatment limitations. ACP forms include advance directives (AD), healthcare directives, living wills for healthcare (LW, LWHC), healthcare DPOA forms, and POLST forms.

Advance directive (AD): This is a term that refers to several specific types of ACP documents, including healthcare directives, living wills for healthcare (LW, LWHC), and healthcare DPOA forms.

DNR or **DNAR:** Do not resuscitate; do not attempt resuscitation (synonymous). Translation: "In the event of cardiac arrest, allow natural death and do not perform CPR."

DNI: Do not intubate. **Intubation** refers to insertion of a breathing tube and initiation of invasive mechanical ventilation.

Code status: An in-hospital physician order specifying whether the patient should receive CPR in event of a cardiac arrest (DNR vs. full code), and also whether the patient should receive intubation and mechanical ventilation in the event of respiratory failure (DNI vs. OK-to-intubate). Full code presumes OK-to-intubate. ("To code" means to have one's heart stop [i.e. cardiac arrest].)

DPOA: Durable power of attorney. In medicine, this usually refers to one's healthcare power of attorney (**HCDPOA** or **DPOAHC**). Individual(s) designated by the patient as healthcare DPOA have statutory authority to make healthcare decisions for the patient if/when the patient becomes incapacitated. In Washington State, healthcare DPOA is documented by a notarized form.

Hospice: A palliative, comfort-measures-only approach to caring for patients with terminal illness. In the US, this usually refers to a specific government-run Medicare program that provides payment for this type of care to eligible enrollees.

LNOK: Legal next-of-kin. This refers to the specific surrogate decision-maker(s) that have been granted statutory authority in Washington State to make healthcare decisions on behalf of an incapacitated patient (RCW 7.70.065).

POLST: Physician Orders for Life-Sustaining Treatment. This is a special type of ACP form that contains portable medical orders to guide emergency treatment (see wsma.org/polst and polst.org). It includes the option for a portable DNR order, and other orders.

General Principles and Practices

Coding Practices

When coding, define boundaries of passages at a "macro" level. Coded passages should be comprised of sentences or clauses at the smallest, up to multiple paragraphs at the largest (e.g. a long GOC discussion). Try to capture enough text to give a reader context as to why it is coded the way you coded it.

We recommend coding notes from each patient's chart in chronological order, so that you understand what has happened up to that point. However, please apply codes based on what is written in the text under reviewed, as opposed to what may be separately documented or otherwise inferred.

It is OK to code non-contiguous text (e.g. coding two passages separately), but please don't go crazy splicing things apart into an inordinate number of pieces.

Coding Hierarchy

Codes in this codebook have one of three purposes:

1. Codes that identify that a GOC discussion took place → Section A
2. Codes to help us develop future instruments to measure quality of documentation of GOC discussions → Section A, sub-codes of GOCD
3. Codes that identify text that is NOT a GOC discussion, but that might be mistaken by a computer for a GOC discussion → Section B

Because some of these goals are subservient to others, we have defined a coding hierarchy for when to apply certain codes, and when certain codes may be ignored.

Please follow the coding hierarchy (next page) when coding.

What if I'm not sure if a given code applies?

There is a special code in Dedoose called FLAG for review that can flag a given coding for further review. We encourage you to always make your best effort coding (i.e. apply the codes as best as you see fit), then apply the code FLAG for review to the passages in question and write a memo containing your questions.

Ideally, the number of flagged codes should decrease over time as you become more familiar with the constructs that the codebook is trying to measure.

GOCD and its sub-codes

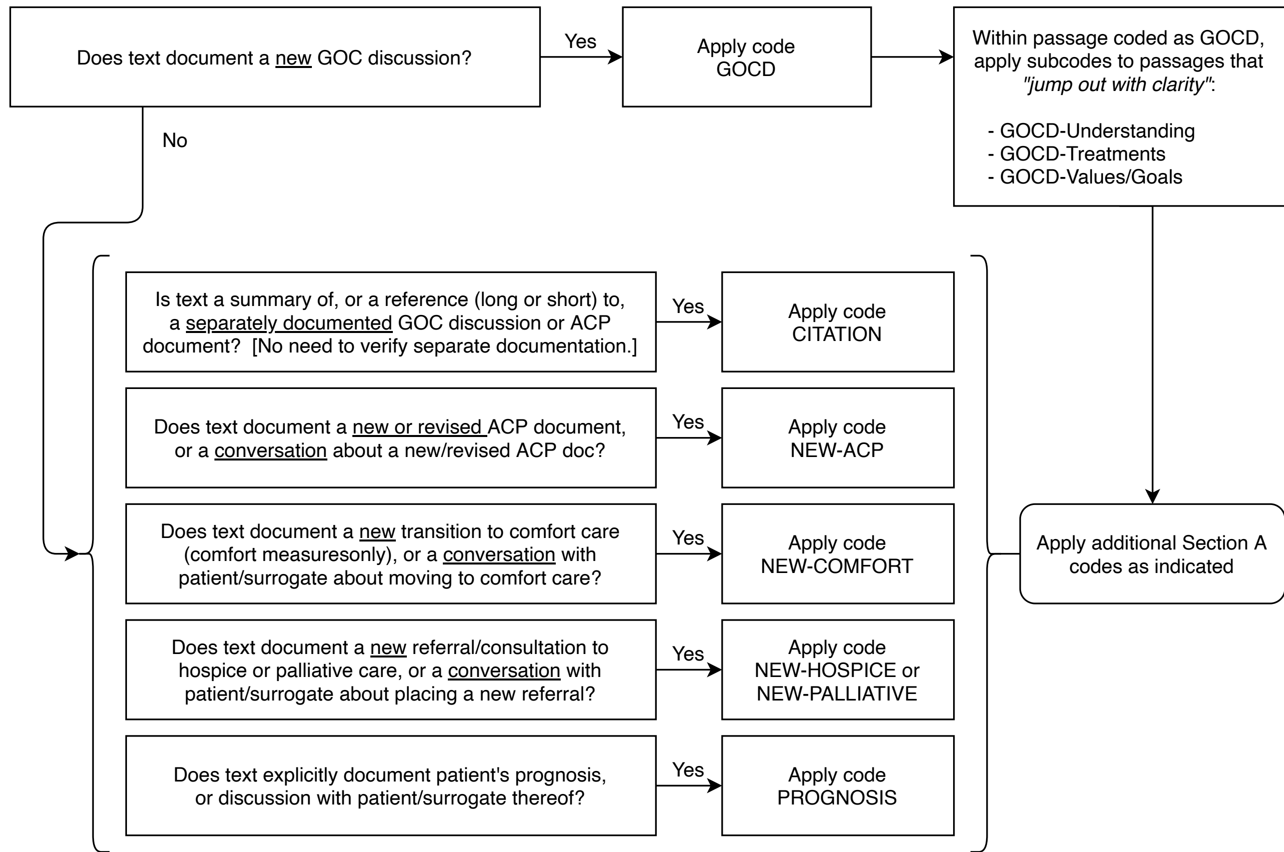
GOCD is the most all-encompassing code. When using it, please tag the *entirety* of the GOC discussion.

Subcodes of GOCD need only be applied within passages that are coded GOCD. Content representing a subcode that occurs *outside of* a GOC discussion need not be coded.

Subcodes of GOCD should be reserved for instances when the defined concept "jumps out at you with clarity." Some GOC discussions may not contain any such passages.

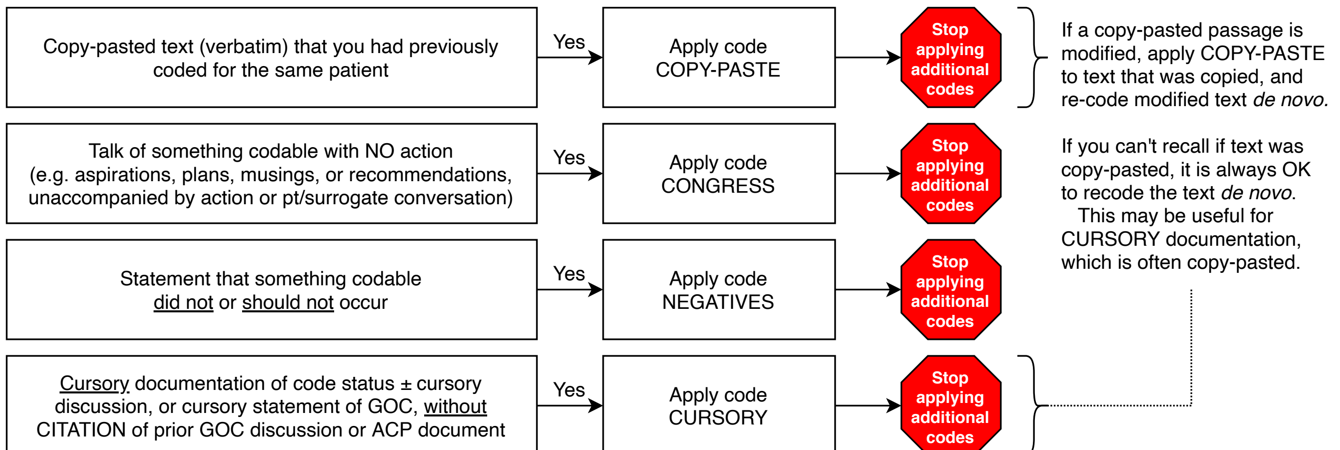
Coding Flowchart

Section A: Codes that measure or infer GOC discussions, or document prognosis



Did you apply one or more Section A codes? → **Yes** → **No need to apply Section B codes to same text.**

Section B: Codes that do not measure GOC discussions



Section A: Codes that measure or infer GOC discussions, or document prognosis

Codes in this section fit into 3 broad categories:

Documented GOC discussions:
CITATION: Summary of (or reference to) separately documented GOC discussions / ACP documents
GOCD: Documentation of *new* goals-of-care discussion

Documentation of things that imply a GOC discussion took place:
NEW-ACP: New or revised ACP document, or conversation re: same
NEW-COMFORT: New transition to comfort care, or conversation re: same
NEW-HOSPICE: New referral to hospice, or conversation re: same
NEW-PALLIATIVE: New referral to palliative care, or conversation re: same

Documentation of prognosis:
PROGNOSIS: Explicit documentation of prognosis
(Strictly speaking, prognosis ≠ GOC discussion; but, we'd like to measure this nonetheless.)

Codes in this section may be nested within each other—for example, codes CITATION or NEW-ACP may be applied to excerpts from a larger passage that is coded in its entirety as GOCD.

GOCD: Documentation of *new* goals-of-care discussion

DEFINITION: GOC discussions talk about "the overarching aims of medical care for a patient" for *when the patient becomes sicker or when they are dying.* This includes, but is not limited to, planning for future hospitalizations, worsening of disease, or end-of-life care.

A GOC discussion may be "informed by patients' underlying values and priorities," and may ultimately lead to or include "decisions about the use of, or limitation(s) on, specific medical interventions." [Secunda et al, JGIM 2019]

Examples of GOCD: **Link to PDF** on PICSI-P SharePoint (secure)

★ Please tag the entirety of the discussion.

→ GOCD sub-codes

Within passages coded as GOCD, please use these sub-codes to tag any clear instances of the following three domains: understanding of illness, treatment preferences , and values/goals.

Sub-codes should be used only when the text ***jumps out at you with clarity*** in these domains.

GOCD-Understanding: Documentation of **preexisting understanding/perspective re: illness**

"What have doctors told you thus far?" This code aims to measure documentation of discussion about the patient or family's global understanding of and/or perspectives on the patient's illness. Assessing this understanding at the beginning of a GOC discussion helps align everyone.
Hint: This type of understanding is usually assessed near the beginning of a GOC discussion.

Examples:

- "Mr. ___'s family understands that he is critically ill and at high risk of dying. They understand that his heart is no longer functioning well enough to support other organs."
- "Ms. ___ has been ill for a long time with worsening CHF and has long felt that this would be the disease that would lead to her death."
- "We discussed the patient's understanding of her illness and her desire to know the results of testing." (Documentation of discussion counts, even though the patient's understanding is not explicitly documented.)
- [I asked her what she heard about what is going on.] "She told me that she heard that she has problems with blood flow in her intestines and that it is causing her pain."

Do not use for standalone documentation of understanding of treatment options or risks/benefits thereof. Understanding of options/risks/benefits (*"What did I just tell you, just now?"*) is a different assessment that often happens near the end of a discussion; it is a poor marker of quality for a GOC discussion, and is often documented for legal assurances.

Negative examples, if occurring in isolation:

- "Patient and family expressed understanding. All questions answered." (Understanding of what?)
- "Family understands he will die without intubation." (This is not an understanding of illness, but rather an understanding of the consequence of death without intubation.)

GOCD-Values/Goals: Discussions about **values and life goals**

Discussions with patients or surrogates about **what they think is most important in life**, or about **specific life results (goals) desired** by patients/surrogates. Patients might prioritize values such as life extension, independence, cognitive capacity, or comfort. They might express life goals of returning home, or living to see a child get married.

Examples:

- "Ms. ___ said that interacting with her family and her husband ___ are priorities. She does not want to suffer, but also prioritizes longevity enough to be willing to give up some comfort."
- "I talked with patient about his values regarding end-of-life care. He believes that life is worth living as long as his heart is beating."
- "Patient prioritizes his quality of life over quantity."
- "Mr. ___ told us that he wants to be able to leave the hospital and go back to his farm."
- "Family hopes for patient to live long enough so that relative from Europe may visit next month."

GOCD-Treatments: Discussions about **treatment preferences or limitations**

Discussions with patients/surrogates about **specific medical treatments**, such as hospitalization, intensive care, life-sustaining treatments, mechanical ventilation, CPR, dialysis, surgery, etc. May include preferences to receive, or to not receive, specific types of treatments.

Examples:

- "Patient desires no CPR, intubation or artificial nutrition."
- "After discussion of resuscitation outcomes, the patient decided to make herself DNR/DNI."
- "At this stage, the patient would like aggressive treatment for illnesses, including a trial of mechanical ventilation. She is ambivalent about CPR vs DNR."
- "Mr. ___ has expressed his wish to continue chemotherapy, despite a high risk of potential complications."

* **Re: the word "comfort":** The word "comfort" may sometimes refer to the treatment strategy of "comfort care" or "comfort measures only." However, if the text is not reflecting an actual, new transition to a comfort-measures-only treatment strategy (which would be coded NEW-COMFORT), you should always code it as GOCD-Values/Goals.

Sometimes, treatment preferences and values/goals may overlap, or occur in the same sentence.

Examples:

- "The patient remains very interested in any treatments that may prolong his life." [Can apply both subcodes to this quote, which reflects a preference for life-sustaining treatments and a value of life extension.]
- "Patient states that he would want to be kept alive using artificial measures as long as he is not disabled in the long term." [Can apply both subcodes to this quote, which reflects a preference for life-sustaining treatments and a value/goal of avoiding disability.]
- "Patient stated today that she would not want aggressive interventions if she were not able to interact with her family." [Can apply both subcodes to this quote, which reflects a preference for avoiding aggressive interventions contingent upon outcomes conflicting with the value of being able to interact with family.]
- "Patient stated that her goals were to be able to recognize and communicate with her family and that she would be okay with living in a nursing home needing help with ADLs for a short term, but not indefinitely." [Can apply code GOCD-Values/Goals to green portion, and GOCD-Treatments to yellow portion.]

Things that are NOT a new GOC discussion:

- Citation of past GOC discussions without a new discussion [Use code CITATION.]
- Citation of past ACP documents without revision [Use code CITATION.]
- Discussions that do not pertain to *overarching aims* for *when the patient is sicker or dying:*
  - "Goal of physical therapy is for patient to be able to walk up 4 stairs prior to discharge."
  - "Patient wishes to take fewer medicines and reduce pill burden. Will stop atorvastatin."
  - "Patient wants to go to Europe but is afraid of flying. Will prescribe propranolol."
- Shared decision-making about routine medical care:
  - "I discussed with pt whether to pursue prostate ca screening. After deliberation, he declined."
  - "We reviewed the risks and benefits of monitoring this lung nodule versus biopsying it. The patient and I agreed to defer biopsy for now and check a follow-up CT in 3 months."
- Routine documentation of consent prior to a surgery or procedure:
  - "The risks/benefits/alternatives to the procedure were reviewed; patient consented to surgery."

Notes:

- Subcodes of GOCD should be reserved for instances when the defined concept "jumps out at you with clarity." Some GOC discussions may not contain any such passages.
- Subcodes of GOCD need only be applied within passages that are coded GOCD. Content representing a subcode that occurs outside of a GOC discussion need not be coded.

CITATION: Summary of (or reference to) separately documented GOCD / ACP doc

Summary of, or reference to, any separately documented GOC discussion or ACP form. Examples:

- "He has been having extended GOC discussions over the past several months that are documented in Epic and ORCA. Overall, he is still ambivalent about whether he wants to continue chemotherapy."
- "Patient was noted to be DNR/DNI during an admission [2 months ago] for COPD exacerbation, at which time she had met with palliative care and decided to continue to pursue all available treatments."
- "I had had a conversation with the patient during her last admission in January, at which time she had expressed the wish to prioritize longevity, but not if it involved a tracheostomy."
- "Patient's POLST, dated [2 years ago], specifies DNAR, Limited Interventions, Antibiotics for comfort."
- "GOC: See palliative care note from [3 days ago]. Family still wants all aggressive care for now but is considering comfort care."
- "Patient's DPOA form reviewed; his designated decision-maker is (sister)."

No need to verify separate documentation. We can take the note writer's word for it.

Nesting inside of GOCD: If CITATION occurs inside a larger GOC discussion [code GOCD], please (1) code the entire GOC discussion as GOCD, and (2) dual-code summaries of past discussions within as CITATION.

CITATION may occur in interim/discharge summaries, as they summarize GOC content from previous notes.

Do not use for *copy-pasted* text. See code COPY-PASTE.

NEW-ACP: New or revised ACP document, or conversation re: new/revised ACP doc

Documentation that a **new** or revised advance care planning document was discussed with patient/surrogate, completed, or revised. Advance care planning documents/forms include: advance directives (AD), healthcare directives, healthcare DPOA forms, living wills for healthcare (LW, LWHC), POLST, and others. Examples:

- "Completed POLST today."
- "Completed POLST with patient. He would not want CPR, but would want limited interventions."
- "POLST form given to patient, will bring back next visit."
- "POLST from 2 years ago states comfort-measures only; son confirmed this."

- “Patient and wife recently completed Living Will today and brought it in. We discussed patient preferences if his illness should progress.”
- “Patient was given a Five Wishes form which we discussed today and I encouraged her to bring this back at our next visit.”

If a decision-maker (DPOA) is being changed or reaffirmed, please apply code NEW-ACP, regardless of whether the paperwork formalizing this change/reaffirmation has been completed. Example:

- “Patient still wants his children to be his decision-makers, as he thinks their relationship is improving.” [This is discussion that would lead to a revised healthcare DPOA designation.]

NEW-COMFORT: New transition to comfort care, or conversation re: new transition

Documented new transition to comfort measures only (comfort care).

- “Patient transitioning to comfort measures only.”
- “I recommended family consider transitioning to comfort care given poor neurological prognosis.”

NEW-HOSPICE: New referral to hospice, or conversation re: new referral

Documented new referral to hospice program or hospice facility.

OR

Documented discussion about new referral to hospice with patient/surrogate. Examples:

- “I recommended patient and husband consider hospice today as she is no longer responding to treatment. They will discuss this over and follow-up next week.”
- “Patient prefers to die at home, I suggested hospice may be helpful.”
- “Patient wishes to stop chemotherapy and asked about hospice.”
- “I will have SW place a referral to Zen Hospice today.”

Negative examples that reflect neither a new referral nor discussion surrounding one:

- “Patient may be appropriate for hospice given his end-stage disease.” [Use code CONGRESS.]
- “94yoM currently on home hospice who was brought to the ED with …” [Do not code. This documentation does not reflect a new referral, as the patient is already enrolled in hospice.]
- “The patient had previously been on hospice, but was discharged from hospice due to…” [Do not code. This documentation does not reflect a new referral.]

NEW-PALLIATIVE: New referral to palliative care, or conversation re: new referral

Documented new referral or consultation to palliative care.

OR

Documented discussion about new referral or consultation to palliative care with patient/surrogate. Examples:

- “Palliative aware of patient.” or “Palliative care to see.” or “PC consult in AM.” [Implies placement of referral.]
- “We recommended consulting the Palliative Care Service for help with these issues, and we broached this option with the patient.”
- “I suggested that talking with a palliative care specialist may help ease his anxiety.”
- “Explained to patient what palliative care is and how they might help.”

Negative examples that reflect neither a new referral nor discussion surrounding one:

- “Consider Palliative Care referral if pain is not managed.” [Use code CONGRESS.]

Do not use this annotation for notes written *by* the palliative care service. (Apart from this code, palliative care service notes should be annotated in the same way as any other note.)

PROGNOSIS: Explicit documentation of prognosis, including unknown/uncertain

Explicit documentation of patient's prognosis, including if it is unknown/uncertain. Examples:

- "Discussed with patient today that the CT scan shows further metastasis and previous tumors have grown despite 3rd-line chemotherapy. Unfortunately, he is no longer responding to treatment and his life expectancy is limited."
- "Patient asked about chances of recovery and we had a long talk about his prognosis and what the future holds."
- "Discussed prognosis with patient."
- "Critically ill, very poor prognosis."
- "Prognosis unclear as there is little experience with this disease process."
- "Estimated Prognosis: Oncologic work-up is ongoing."

Section B: Codes that do not measure GOC discussions

These codes are intended to help identify content that does not represent a GOC discussion, but that may contain similar verbiage to a GOC discussion.

★ If a passage bears any Section A code (e.g. GOCD, CITATION, NEW-ACP, etc.)**, you do not need to apply any Section B codes.**

CURSORY: Cursory documentation of code status, or cursory statement of GOC

Standalone, cursory documentation of code status, or cursory statement of GOC (e.g. "hospice", "comfort care"). Commonly encountered near the end of a note, in a templated "checklist" section; sometimes may also be encountered in a Code Status note. Examples:

- "Code status: FULL by default"
- "GOC: DNR, OK to intubate"
- "His code status is full code, no intubation."
- "GOC: Comfort measures only"
- "GOC: On hospice"

Also includes documentation accompanied by **cursory** (one-line) condition or context. Examples:

- "GOC: DNR/DNI, confirmed with pt but she is ok to be Full Code during surgery"
- "Code status: DNR/DNI, confirmed on admit with patient and son"
- "Code status: Full code, although patient would not want prolonged artificial support"

Also includes the following auto-template that may appear in **interim & discharge summaries:**

ADVANCE DIRECTIVE:

Patient has Advance Directive: No

List of Health Care Directives Scanned into UW Medicine Hospital Record:
Adv Dir Flowsheet 04/23/12
Adv Dir Flowsheet 09/11/14
POLST 02/21/15

Do not use for in-depth discussions: If there is clear evidence of a deeper discussion, please use code GOCD (if documenting a new GOC discussion) or CITATION (if summarizing a previously documented discussion), even if the documentation occurs in a checklist section. Example:

- "Code status: Full code. I discussed with daughter utility of CPR given poor prognosis; for now she desires all available medical care for her mother but she would not want patient to receive prolonged or indefinite life support." [Use code GOCD.]
- "GOC: See palliative care note from [3 days ago]. Family still wants all aggressive care for now but is considering comfort care." [Use code CITATION.]

Do not code documentation of family contacts / DPOA / legal next-of-kin in the checklist.

CONGRESS: Talk of something codable with NO action

All talk and no action! When a note writer documents their aspirations, plans, musings, or recommendations to do something codable (hold GOC discussion, talk about / refer to hospice, etc.) **BUT** has not actually *done* anything, or even *talked about it* with the patient/surrogate.

Etymology of code: "What's the opposite of progress?" "Congress."

Examples:

- "Patient critically ill with poor neurological prognosis. Will need to visit with family re: GOC."
- "GOC pending family meeting, likely in AM."
- "Plan: Consider Palliative Care referral if pain is not managed."
- "At next visit, will need to revisit with patient what his GOC are in light of severe illness."
- "Recommend palliative care consultation given poor prognosis." [Written by a consulting team, who are not actually placing the palliative care consult nor discussing it with the patient/family.]

NEGATIVES: Statements that something codable did not occur

Clinician's notation that a GOC discussion, ACP document, or other coded element did not occur. Examples:

- "We did not discuss goals of care today."
- "POLST forms was not available."
- "Palliative Care referral was not introduced today."
- "Patient does not want to discuss code status."

COPY-PASTE: Previously-coded text that was copy-pasted forward

Previously coded text (any code) that was copy-pasted forward into the record. By copy-paste, we mean that the note writer literally copy-pasted stuff verbatim into the record, without any modification to the pasted text.

The purpose of this code is to be a time-saver, to reduce duplicated efforts. Whether or not to use it (as opposed to coding the text *de novo*) is left to the discretion of the abstractor.

If you cannot recall whether a given passage was copy-pasted or not, it is always acceptable to recode the passage *de novo*.

> This caveat may be useful for CURSORY documentation, which is often copy-pasted; I mention this because it may be painful to have to look back every time to see if what's in the CURSORY documentation has changed since the last note. So, if it is helpful to your workflow, it is okay to code each instance of CURSORY documentation as CURSORY in lieu of COPY-PASTE), even if it is in fact copy-pasted from note to note.

What if they changed the text? If the note writer copies and pastes a passage, *then addends or modifies it*, please apply COPY-PASTE to the text that was copied verbatim, and code the modified/added text *de novo*.

What if they summarized some other text? If the note writer is summarizing something that was documented elsewhere, you should apply code CITATION.

Special circumstances and FYIs

Cerner fields: In the Cerner EHR system, an underscore ("_") is a field that a user can "jump" to by hitting F3. Underscores can therefore represent fields in note templates that were not filled out or checked off.

Cerner checklists: Some note templates contain checklists to simplify routine documentation. "[x]" means the writer checked off whatever is next to it; "[_]" means the writer left it unchecked. In some templates, the brackets are omitted. Please only code checked items.

Code attending attestations as if they were their own notes: In general, attending attestations should be coded as if they were independent notes. For example, when a GOC discussion is documented and the information is recapitulated in multiple sections of the same note (e.g. resident documentation, then attending attestation), please code each instance as if it were a unique GOCD. Whereas, if an attending attestation refers to a discussion at which the attending was not present, use CITATION.

Apply CURSORY to imported list of ACP Documents: By default, discharge summaries and interim summaries contain a templated list of imported ACP documents (pictured below). Please apply code CURSORY to this documentation.

ADVANCE DIRECTIVE:

Patient has Advance Directive: No

List of Health Care Directives Scanned into UW Medicine Hospital Record:
Adv Dir Flowsheet 04/23/12
Adv Dir Flowsheet 09/11/14
POLST 02/21/15

★ **Please ignore the palliative care data collection checklist** (pictured in part below):

ATTENDING TO COMPLETE (FOR DATA COLLECTION)

Date consult requested: _

Location at time of referral (choose one):
_Med/Surg
_Telemetry/Step Down
_Critical Care
_Emergency Department
_Acute Rehab
_Other: _

Reasons given by referring provider for initial PC consult (chec
_GOC discussion/ACP
_Pain management
_Other symptom management
_Withdrawal of interventions
_Comfort care
_Support for patient/family
_Hospice referral/discussion
_No reason given
_Other: _
_Patient not seen because: